

State of Connecticut Department of Developmental Services



Terrence W. Macy, Ph.D. Commissioner

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To: Adult Siblings of an Individual with Intellectual/Developmental Disability or Autism

We would like to share information and invite you to participate in upcoming opportunities specifically for adult siblings. Siblings of all ages are crucial components of an individual's network of support. Adult siblings have specific questions, unique challenges and sometimes genuine fears as they consider how to be supportive to their siblings, as parents age and resources diminish.

On the afternoon of February 10th 2014, Katie Arnold from the Sibling Leadership Network came to DDS as an invited speaker. She spoke to over 30 DDS managers and directors about various ways a state agency can support adult siblings in supporting one another. She reviewed the steps to starting a chapter of the Sibling Leadership Network in Connecticut and affirmed her willingness to support Connecticut Adult Siblings in these efforts. Later that evening Ms. Arnold shared an evening with approximately 20 individuals including representatives from private agencies, family support networks, and adult siblings. There were attendees from all parts of the state, some of whom, were engaging with DDS for the first time. It was a wonderful evening of sibling networking and information sharing. Individuals were interested in ongoing conversation and activities to support siblings. For example there were suggestions such as: developing a list-serv; use of social media to assist in maintaining connection; understanding guardianship and conservatorship; additional networking activities; etc.

As a follow up to these events, on April 22, 2014 at Adult Siblings throughout Connecticut participated in a conference call facilitated by the Department of Developmental Services. The goal was to assist adult siblings to build connections through shared experiences, stories, and knowledge.

While attendance was low, the conversation was information packed and expressed to have been beneficial to all participants.

During the one hour conversation we discussed:

- Challenges of supporting a sibling living in CT while living out of state
- Ways to support your sibling living in his/her own apartment but is lonely
- What do you do when you believe your sibling should be in a group home?
- The impact of supporting your sibling has on your spouse/partner marriage
- How do you travel, take some "me time" when you have to always care for your sibling
- What do you do when your parents believe the sibling should remain in the home and you don't
- How do you deal with parental pressure to become the caretaker for your sibling and you don't really want to
- The guilt when your sibling moves from home to a group home after you become the guardian

- Expressed need for more help to understand the role of sibling
- After becoming guardian of an adult sibling, it's difficult to figure out what questions to ask because you don't understand what is going on
- It is very difficult to complete long term planning because we don't know what will be available long term

The group raised these topics while delivering words of support, ideas, suggestions, and validating the feelings and experiences of one another.

The participants agreed that these conference calls are a convenient means of maintaining connection and also requested that the new DDS family website http://www.ct.gov/dds/cwp/view.asp?a=2042&q=518842&ddsNav=| is updated as information for adult sibling is collected.

The participants also suggested links to trainings and frequently asked questions should be made available on the sibling site.

This coming Fall 2014, DDS will host a panel presentation and discussion regarding the topics highlighted above. The date is TBD.

We will host future conference calls between now and the date of the event, to assist in the planning. It is imperative that we collaborate with siblings to create forums for adult siblings to discuss the specific needs.

The conference calls will focus on determining topics, presenters, along with some basic event logistics.

These calls are open to all adult siblings across CT.

The next call will be held on August 19, 2014 at 6pm.

If you are interested in the call please email Julie Bouchard at <u>Julie.bouchard@ct.gov</u> and she will give you the call in number. There is a maximum capacity, so please remember to register ASAP and call in on time.

Please share this with any adult siblings that you know. Also, we invite you to send us email addresses of anyone that would like to be added to our email distribution.

For more information contact Lakisha Hyatt at Lakisha. Hyatt@ct.gov or Jenifer Bogin at Jennifer. Bogin@ct.gov

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